

United Press International, April 2, 2007

WASHINGTON, April 2 (UPI) -- Valen Cover-Sheriff was diagnosed with polycystic kidney disease at 10. By the time she reached college, her kidneys had grown so large with cysts that she looked pregnant.

"The hospital soon became my home," Cover-Sheriff told a briefing held by the Congressional Kidney Caucus. "I had constant blood in my urine and was put on steady pain medication. My abdomen grew so bloated because of all the cysts."

PKD is the most common genetic life-threatening disease in the world and currently has no cure, affecting 600,000 Americans and about 12 million worldwide. It's found equally among different races, ages and genders. While a normal kidney is about the size of a fist, PKD increases each kidney to the size of a football, for a combined kidney weight of 50 to 75 pounds.

There are currently 14 trials searching for a cure, an improvement from no clinical trials a few years ago, said Dr. Ted Steinman, a professor at Harvard Medical School and PKD expert.

"We're making headway in preventing progression of the disease slowly with good quality care, (which) is the end result of research," said Steinman.

The Kidney Caucus was founded by Reps. Jim McDermott, D-Wash., and Mark Kirk, R-Ill., and aims to inform public policy and aid individuals on kidney diseases. Public funding on research for preventing kidney disease is low compared to other diseases, said Steinman. Federal funding for PKD research measures out to \$53 per affected person, while other common genetic diseases equates to \$1,500 per affected person. In 2005, the National Institutes of Health only devoted \$35 million to PKD research, even though it spent \$2 billion in Medicare and Medicaid costs for treatment.

Funding would save money and lives in the long run, Steinman said. "PKD is an example of investing five and saving 10," said Steinman.

"We know research is going to answer the questions of PKD -- that's where the cures are going to come from," said Dan Larson, president and CEO of the Polycystic Kidney Disease Foundation. The foundation has generated money for research primarily through patients or relatives of patients.

The only treatment now for PKD is a kidney transplant. Cover-Sheriff, for instance, is lucky to be alive -- a family friend matched her blood type and was willing to donate a kidney. Every year, 3,000 people die while waiting on a list for transplants, said Larson. The average wait is about four to five years.

Larson told UPI that getting a kidney donation in the United States is difficult because of laws requiring donors to give registered consent before death.

Despite the 70-plus blood transfusions and 40 inches of scars covering her abdomen, Cover-Sheriff is glad to be alive and share her story with others. She realized she can't take her health for granted.

"Without your health, there is nothing else," she said.